

February 2018

## Effective Community Engagement Strategies: The Voices of Injection Drug Users

Elizabeth D. Gilbert

*University of Northern Colorado*

Devin Laedtke

*University of Colorado, Denver*

Teresa A. Sharp

*University of Northern Colorado*

Stephanie Wood

*Tacoma Pierce County Health Department*

Lisa Raville

*Harm Reduction Action Center*

Follow this and additional works at: <https://digitalcommons.northgeorgia.edu/jces>

---

### Recommended Citation

Gilbert, Elizabeth D.; Laedtke, Devin; Sharp, Teresa A.; Wood, Stephanie; and Raville, Lisa (2018) "Effective Community Engagement Strategies: The Voices of Injection Drug Users," *Journal of Community Engagement and Scholarship*: Vol. 10 : Iss. 2 , Article 6.

Available at: <https://digitalcommons.northgeorgia.edu/jces/vol10/iss2/6>

This Article is brought to you for free and open access by Nighthawks Open Institutional Repository. It has been accepted for inclusion in Journal of Community Engagement and Scholarship by an authorized editor of Nighthawks Open Institutional Repository.

# Effective Community Engagement Strategies: The Voices of Injection Drug Users

Elizabeth D. Gilbert, Devin Laedtke, Teresa A. Sharp,  
Stephanie Wood, and Lisa Raville

---

## Abstract

Academic and community interactions are often conducted with good intentions. However, there is exploitation risk for populations engaging in illegal activities. Collaborations with injection drug users (IDUs) can highlight their expertise and support progressive research. The objective of our research was to use community-based participatory research principles to give voice to IDUs, define community, and recommend authentic engagement strategies. In Phase 1, 10 focus groups (n=33, ages 25–64) helped define community and collaborative partnerships. In Phase 2, community forums with 13 additional IDUs provided feedback on focus group themes. Results: (1) primary themes defining community—geography and social networks; (2) community qualities—respectful, accepting, outcasts, and welcoming; (3) engagement recommendations—incentives, recognizing potential for contributions, treating IDUs respectfully, using research results for positive benefit. Conclusions: Providing voice to marginalized communities allows for self-definition, description of needs, and authentic engagement recommendations. This information is crucial for developing effective programs and creating sustainable collaborations between IDUs and academics.

Although many researchers set out to understand the experiences of vulnerable populations, authentically engaging with these communities is a frequently overlooked strategy. Authentic engagement increases the level of community involvement and collaboration and thus positively impacts the level of trust (National Institutes of Health, 2011). The concept of community is a critical component in how individuals experience their daily lives; however, “there is a lack of consensus on a clear definition or set of criteria that define community across diverse situations” (Paveglio, Boyd, & Carrol, 2016, p. 1). It is crucial that researchers and service providers enter marginalized communities with a priority of understanding as much as possible about these groups.

Research among vulnerable populations often fails to accurately represent the population of interest (Wilson & Neville, 2009). Researchers are often outsiders who create the agenda and use their own lenses for observation and interpretation, which fails to engage vulnerable populations. This research approach increases the chance for exploitation of vulnerable populations. In order to gather an accurate reflection, it is necessary to improve the inclusiveness and efficacy of research within these communities. In order to reach this goal, community partners must be involved in every aspect of the research project including design, implementation, evaluation, and dissemination.

If population members are not included in the initial stages of the research process, there is a strong likelihood that the research can worsen vulnerability within these populations (Wilson & Neville, 2009). In an effort to reduce vulnerability, engaging community members provides an opportunity to self-describe the qualities that make them who they are. Community-based participatory research (CBPR) is a methodology that enhances engagement efforts to reduce the misrepresentation and exploitation of researched populations and improves health and well-being through social change and meaningful community engagement (Bell & Salmon, 2011; Hayashi, Fairbairn, Suwannawong, Kaplan, Wood, & Kerr, 2012). CBPR requires equitable, collaborative partnerships between community members, community-based organizations, and researchers in all interactions. Partners contribute their expertise and knowledge and share in the decision-making and ownership of projects (Viswanthan, Ammerman, Eng, Gartlehner, Lohr, Griffith, Rhodes, Samuel-Hodge, Maty, Lux, Webb, Sutton, Swinson, Jackman, & Whitener, 2004).

It is important to note that communities are more than a grouping of individuals. Social networks often generate unique subcultures with unique collective needs that appear incongruent to what researchers typically identify as community priorities (Murphy-Berman, Schnoes, &

Chambers, 2000). As a result, core identifying dimensions of community and their psychosocial contexts are necessary before successful collaborations can develop (Chilenski, Greenberg, & Feinberg, 2007; McMilliam & Chavis, 1986). CBPR has been a powerful method for addressing health and psychosocial issues in a variety of communities (Mooney-Sommers & Maher, 2009; Rhodes, Hergenrather, Wilkin, & Jolly, 2008; Sullivan, Hassal, & Rowlands, 2008).

### **CBPR and Injection Drug Use**

As a result of successful use of CBPR with other diverse groups, inclusion of CBPR research methods and principles is essential for successful research within the IDU community. The use of CBPR approaches is recent with IDU, a population that is impacted by substance abuse, extenuating mental health issues, poverty, stigmatization, and psychosocial marginalization. As a result, effective implementation of CBPR within these communities is unclear. However, CBPR allows researchers and service providers to work collaboratively with community members and provide authentic engagement that includes the IDU community in shared control of the research process. As a result, the IDU community develops an investment in identifying and advocating for their own service needs (Shaw, Lazarus, Pantalone, LeBlanc, Lin, Stanley, Chepesiuk, Patel, Tyndall, & the PROUD Community Advisory Committee, 2015).

One case study conducted with IDUs in Thailand demonstrated the positive impact of the CBPR methodology when working with this marginalized, and often invisible, population. The collaboration fostered a better understanding of an IDU community and connected the IDUs to important services (Hayashi et al., 2012). Investigators reported that few studies had successfully captured the dynamics of IDU community participation in health research, and prior studies primarily focused on health promotion and education among IDUs. The results of this study suggest further investigation is necessary to optimize CBPR engagement strategies when working with IDU communities (Hayashi et al., 2012). Additional research should continue to include IDUs' perception of researcher/participant social exchange, shared decision-making, and data ownership.

While exemplifying this type of collaborative community project, the current study uses CBPR methodology and gathers perceptions and input from clients of the Harm Reduction Action Center

(HRAC), regarding strategies researchers and service providers can use to more effectively enter and work within IDU communities. Understanding how the community defines itself and wants to actively engage (or not) with researchers allows for more successful research, interventions, and service programs.

The HRAC in Denver, Colorado seeks to “educate, empower and advocate for the health and dignity of Metro-Denver’s injection drug users and affected partners in accordance with harm reduction principles” (see <http://www.harmreductionactioncenter.org/index.html>). Harm reduction principles aim to reduce the negative consequences of drug use affecting the individual, families, and the larger community. This approach recognizes the prevalence of illicit drug use in our communities and accepts unsafe use of these drugs is an inevitable occurrence within our society (Reid, 2002). HRAC promotes public health by ensuring that people who inject drugs are educated and equipped with tools needed to reduce the spread of communicable diseases, such as HIV and Hepatitis C, and eliminate the proliferation of fatal overdoses.

Thorough evaluation of community dimensions is crucial for successful community engagement. Researchers’ and community providers’ assumptions about the IDU community can undermine the ability to effectively engage IDUs in research/community partnerships and effectively evaluate the contribution of these collaborations. The focus of the current project was to gain insight from IDUs into both desirable and ineffective characteristics of researchers and their institutions. Ultimately, this study aimed to strengthen the connection between community and academia. The specific aims of the current study are:

1. Give voice to an historically marginalized community
2. Define what “community” means to IDUs
3. Recommend effective engagement strategies for researchers and providers partnering with IDU communities

### **Methods**

#### *Community Partnerships*

The partners in this project were the Colorado School of Public Health at the University of Northern Colorado (CSPH@UNC), HRAC, and the Colorado Department of Public Health and the Environment (CDPHE). The initial partnership between HRAC and CSPH@UNC began when an

HRAC staff member was a graduate student in the CSPH@UNC master of public health program. Upon graduation, she began a job at CDPHE and approached both CSPH@UNC and HRAC about a collaborative community-engaged project that would allow members of the Denver injection drug using community to tell their stories. Another CSPH@UNC graduate student and co-author was involved in the analysis and interpretation of the stories provided by the Denver IDU community. The University of Northern Colorado Institutional Review Board and HRAC administration approved this project. The Colorado Department of Public Health and Environment provided funding support.

Since 2002, HRAC has been Colorado's primary provider of services and HIV/HCV prevention to IDUs in the Denver community. To date, HRAC has more than 4,100 unique clients, making it the largest syringe access program in Colorado. The most accessed client-based services provided by HRAC include vein care education, HIV and Hepatitis C testing, and Naloxone administration and training. Academically, HRAC has served as a frequent site for educational volunteer opportunities for both undergraduate and graduate students at the University of Northern Colorado, as well as providing guest lectures about harm reduction since 2009. In addition, HRAC is a community organization that is continuously engaging with lawmakers, healthcare providers, law enforcement, and the general Denver Metro community in an effort to work toward a healthier Colorado.

HRAC, as the community stakeholder for this project, was involved in all phases of this work, including study design, recruitment of participants, implementation of focus groups and community forums, evaluation, data analysis, and dissemination. A faculty member of CSPH@UNC and a staff member of HRAC and CDPHE designed the project, and once created, implementation of the focus groups and the community forums occurred at HRAC. CSPH@UNC faculty, students, and a CDPHE staff member analyzed focus group data and feedback provided at the community forums.

### *Phase One*

The initial phase of this project concentrated on defining community and fostering meaningful participation in health research through focus group discussions. Academic and community partners developed focus group questions to identify participants' perceptions of how researchers and

service providers have engaged the community, how members define their community, and what collaborative partnerships should entail. Questions developed by the CSPH@UNC faculty and the HRAC staff kept the appropriate literacy levels of the community participants in mind.

Participants included 26 males and 7 females ranging in age from 25 to 64. Recruitment efforts used flyers posted at the HRAC, as the organization focuses on the needs of IDUs in the Metro Denver area. Participants initially completed a brief survey to collect demographic information, residential status, and drug injecting history.

While most (n=21) participants had injected within the past 30 days, it was mandatory that participants abstain from drug use at the time of the focus groups. Ten focus groups were comprised of two to seven participants who each received a gift card as compensation for their time. Focus groups facilitators included the co-investigators and an IRB-approved participant who was a client and volunteer at the HRAC.

Following transcription of audio recordings, co-investigators analyzed focus group data by identifying categories of information based on the themes that emerged. An embedded analysis searched for patterns in the transcripts from focus group responses related to community definition and strategies for meaningful engagement (Wolcott, 1994). Embedded analysis is a method used when there is more than one sub-unit to analyze (Creswell, 2007). This analysis enabled investigators to identify relevant themes that emerged from respondents in these sub-units and from select questions asked during both the focus groups and the community forums. Focus group questions included:

1. When you think of the word community, what does the word community mean to you?
2. Can you tell us about a particular time when you felt part of a community?
3. Why is it important for a person to belong to a community?
4. Would you tell us about the main community that you most identify with—what does that community look like?
5. What important qualities do members have in your community?
6. What have relationships between your community and researchers been in the past?
7. What needs to be in place for researchers and your community to be able to work together?

8. Imagine if a researcher came to your community and said, “We want to do a study on something that would help your community.” What would your community suggest?

### *Phase Two*

During phase two, community and academic partners held two community forums with IDUs who were not focus group participants. CSPH@UNC investigators and the HRAC staff co-facilitated the forums, and CSPH@UNC investigators and the HRAC staff developed four questions or statements from information garnered in the focus groups. Forum questions and statements were as follows:

1. Researchers find out what the important issues are in our community by...
2. Ways that researchers could come into my community's world would be....
3. How could researchers explain to you why they want to study your community?
4. How can researchers find out what issues matter to your community?

Posters mounted on the walls of the HRAC displayed each community forum question or statement. Groups of three to four participants rotated throughout the stations where they provided written feedback to each question or statement until they had provided input at all stations. After completion of the rotations, participants discussed the interpretation and ownership of study findings, while encouraging community exploration of what collaborative partnership in health research could entail. Interpretation responses for each question were recorded on flip charts and later reviewed by the investigators.

The community forums provided an opportunity to explain, confirm, and/or challenge definitions of community from initial focus group data. Participants of the community forums also approved or challenged the focus group recommendations to engage IDUs in meaningful collaborative research, which follows the CBPR model of disseminating research findings to the community and encouraging their response. The comments received from IDU partners were helpful in confirming what we learned in focus groups, related to how the IDUs defined their community, and provided recommendations for how outsiders should respectfully enter their community.

### *Identification of Emerging Themes*

Investigators began with raising generative questions to assist in guiding the research. These questions guided the semi-structured conversations that took place in each of the focus groups. Throughout data collection, the investigators identified themes as they emerged. These themes broadly described the responses provided by participants. Qualitative data analysis focused on identifying reoccurring themes voiced by IDUs using grounded theory. Grounded theory is an approach for developing themes grounded in data gathered and analyzed in a deliberate process (Corbin & Strauss, 1990). Resulting focus group themes were presented to community forum participants for a comparative analysis of the initial themes.

### **Results**

There were 46 IDUs (33 focus group participants, 13 community forum participants) who participated in the project. The demographics of study participants are representative of the HRAC's current client population and the Denver Metro Area's IDU population. The two-phase format of the research project allowed for an historically marginalized community to express themselves, voice their concerns, and develop a collaborative relationship with the HRAC staff and CSPH@UNC investigators.

### *Qualitative Results*

The following themes emerged from the voices of focus group and community forum participants.

#### **1. Defining community**

A primary objective of this project was to identify how IDUs defined community. Focus group participants addressed what the word “community” meant to them. Three predominant community definition themes emerged: Geography, Social Networks, and Community Characteristics. It is important to note that the IDU community typically has their identity defined for them by society. This was a time the IDU community could use their voices to define their community for themselves.

### *Geography*

The geographical context in which the participants framed their communities is a primary theme that emerged when defining themselves. This illustrates awareness of the diversity of locations in which members of the community

reside, socialize, support each other, and engage in activities necessary to support their addictions. One participant said community groups split into “downtown on the mall, you’ve got the mall rats, or the park crew. There’s different cliques all throughout town. There’s the west end, the south end, north end and east end. It’s all different little cliques.”

### *Social Networks*

We often heard community described as the “feeling [of being] a part of something”. As a community that is often marginalized, “feeling a part of something” was a new experience for many who participated in this project. The experience of marginalization is what makes the HRAC a place that many of the participants accessed and referred to as a place where “they belonged.” For example, one participant said, “... we all have our community here.” Another said, “...in that group that kind of made me feel like I belonged. I got a sense of identity out of it.” This sense of belonging for the IDU community is one of the intentions of the HRAC.

### *Community Characteristics*

These indicators did not refer to a definition, but rather to the characteristics of the community important in identifying Denver Metro IDUs and how varying roles contribute to their defined community. Many participants, particularly those who were homeless and/or living in camps throughout the city, talked about taking responsibility for each other by sharing resources and responsibilities. Participants discussed working in “teams” each day and dividing up the responsibilities necessary to help each other get food, obtain what was necessary to get high, and do tasks such as laundry. A method they described that is often used to obtain needed resources was to “fly a sign to get money.” This is illustrated by the following comment, “I had four friends that I camped with, and we all had responsibilities for the day...We all had something to do. ...if someone failed their mission for the day, something would go haywire.”

Participants also reported conflicts between the necessity of being dependent upon others in the community, and at the same time, being concerned about the need to be reliant on others. Regardless of the characteristics used to define community, many of the participants found community to be something that lacks dependability. An absence of dependability could

lead to some or all of the critical tasks going uncompleted. One participant described the purpose of each task as a means to make sure that every team member received what was necessary to meet the needs of their addictions and get high, but ultimately they need to consider their own needs first. As one participant described it:

The heroin community is a crooked community. I was going to say that you can talk to and that you got somebody, you know, but you really don’t. Unless you got a shot in the rig, nobody wanna hear your crap. I’m just as treacherous as they are. We’re all backstabbers.

## **2. Qualities of “my” community**

Four qualities emerged from focus group discussions that were important descriptors of how IDU community members described themselves and other members of their communities: accepting, welcoming, respectful, and outcasts. While the first three descriptors indicated ways in which IDU communities and the HRAC responded to those who entered their community, the last was the common quality many of the participants used to describe themselves and others in their community. “When I moved to Denver I felt more accepted here than anywhere I’ve ever lived, even more than my family. ...I came here [HRAC] and I met people who didn’t care [that I was an IDU].” However, other responses showed some IDUs did not see themselves as members of community. “I’ve been on and off the streets. You’re not part of community. If anything, I guess you are a part of a community but you’re the outcast. People just think you’re a parasite.”

## **3. Why it’s important to belong to a community**

Although some respondents indicated they were “outcasts” in society, it became increasingly clear during the focus groups that individuals found a sense of family, stability, safety, and belonging through their own community connections. While the quotes that follow are explanations of participants’ beliefs of the importance of community belonging, the issue of addiction made finding that sense of belonging complicated. In addition, the participants explained that they did not belong to just one community. Something they welcomed was finding a group that could provide them stability and belonging, along with an opportunity to contribute. “I come from a lot of different communities. ...um,

to be a part of a community gives me a sense of family, stability. Not just being out there and, you know, being alone. In a community, I have friends, acquaintances.” Another participant expressed, “I need to know that someone wants me around. I like to feel like I’m contributing something. I need to know that I’m needed, and that I’m wanted, and that I’m welcome.”

#### **4. How would you suggest researchers/service providers build relationships with and identify the needs of your community?**

A goal of this project was to give IDUs an opportunity to recommend strategies to researchers and service providers for ways that they can more effectively engage with IDU communities. When asked, “How would you suggest researchers and service providers build relationships with and identify the needs of your community?” it was clear that many participants were hesitant to answer. When asked about this hesitation, participants provided general agreement that no one had ever asked for their opinions before research was conducted. They also indicated if one of the investigators had not been a long-time partner with the community, it was unlikely that participant responses would have been as forthcoming. This insight is valuable to future researchers wanting to engage with IDUs and other communities in which they are not members.

Since trusted individuals were a part of the research team, the answers and insights provided by the participants serve as a “how-to” list for outsiders seeking successful engagement in an IDU community. Participant suggestions included providing incentives, treating IDUs respectfully, understanding them to be more than just drug users, and using the information collected to make something good happen. In regard to providing incentives, one participant talked about his interaction with a photographer wanting to do a photojournalism piece about the IDU community. His response came from the responsibilities he had to his “team” that required him to contribute resources needed each day. His comments came from the perspective of “time is money”:

He’s doing like this photograph and interview with addicts. And I talked to him yesterday. I said, “hey man, I’ve been thinking about this (photo project). Is there any sort of compensation?” He’s like “no.” I was like, really? If I’m spending time with you for free when I could be out

hustling for money so I can stay well, it’s hard, it’s really hard.

Other participants felt that researchers and practitioners should have considerations of the difficulties experienced by individuals with addiction and those facing homelessness. They felt the only way to begin to understand what their life is like on a daily basis is to spend time with them:

It seems like people see a lot of homeless people and think, “that person wants to be homeless.” They don’t wanna be homeless. They’d know (if they spent time getting to know us). They’d understand better what it’s like to be a drug addict.

We often heard participants express a desire to see researchers and practitioners use the information they gather to make something “good happen.” Participants’ experiences to date had only been with those who seemed interested in getting information that never resulted in any positive changes for IDU communities. Knowing that something positive could help their community made participants more interested in contributing. However, the “good” did not necessarily have to provide changes in their local communities. Contributions could also provide changes for society as a whole. “Why did we give our time to this [the study]?” one participant said. “Because we want to know what benefit it has to somebody else. That’s what research is supposed to be, is a benefit to somebody else, right?”

Another said:

I’d like to see the actual studies being done, the long run, ...how it’s gonna help us, the people that are being studied? I mean sometimes there is so much studies and all this studying going on, like what’s the point of all of this? ...it’s like the same \_\_\_\_ ...[H]ow is this study gonna benefit heroin users in the end?

#### **5. Why is it important to treat members of the IDU community ethically and with respect?**

Distinct themes emerged from participant responses related to ethical and respectful treatment of the IDU community. The participants in this study provided insightful information from their previous interactions with those “researching” their community. Their responses reiterated the need for outsiders entering their communities to

accept that classroom material does not usually transfer to the streets, and the only way to gain the insights necessary is to spend time getting to know the community. “Just open-mindedness from both sides. To understand that researchers are coming in to do a job. And researchers need to understand whatever they learned in school isn’t necessarily the truth on the streets,” said one participant.

One way that participants suggested researchers learn more about them is through field-based experiences to develop relationships with the community. Participants indicated this would provide insight regarding what day-to-day life is like for their community members. As one said, “I think that ...to, like, gain experience, like, to spend a week in the camp before they come to interrogate... and then they’d have a better understanding of what those people living in the camp are going through.”

In addition to providing insights and information to the researchers, participants were also interested in learning about the outcomes of the work that the partnership provided. This reinforces their belief in the importance of bi-directional learning.

...[B]ut the end result was to help us, but it doesn’t seem like that ever happens. It’s just the next thing after, and the next thing after, so maybe to see the results of the study... It makes you feel like, ‘alright, I did something’ but if you sit around and just get asked the same questions over and over by people who don’t even know... (a participant).

It is important for researchers and service providers to understand that the way a community was treated in the past impacts current collaborations. If respect was previously lacking in interactions, participants could be left feeling exploited, which influences current opportunities for engagement. “It’s Tuesday and their boss says, ‘You have to go talk to heroin addicts today,’ and they’re like ‘S---!’ Sometimes they make us feel like that. I’ve felt like that. Like I’m a guinea pig.”

## Discussion

This study illustrated IDUs are a community and not just individual addicts. Respondents described the strength and benefits of creating their community, supporting their needs through resources and responsibilities, and advocating for their future. Participants’ responses mirrored how

Paveglio et al.(2016) previously summarized Tonnie’s (1957) structure of society, which is to “gain access to resources, bear collective burdens, and form networks of support or interaction” (Paveglio, et al., 2016, p.5).

A focus on individual participant ethics has allowed what is often referred to as “helicopter research methodology” where academic careers advance by collecting data without a sense of responsibility to give back to the community (Flicker, Travers, Guta, McDonald & Meagher, 2007). As a result, some methodologies researchers choose to use can unintentionally contribute to the stigmatization experienced by vulnerable communities. In addition, researchers may base their project conclusions on academic benefit while ignoring project results that benefit the community. Because of psychosocial marginalization and disenfranchisement, IDUs are particularly vulnerable to such research methods, and easily feel over-researched and exploited. Thus, it is crucial to discuss the ethical treatment of IDUs by outsiders.

Through participants’ reports of prior research experiences, respondents for this project provided invaluable descriptions of desirable and ineffective characteristics of researchers, along with the importance of social connections between community and academia. These descriptions provide context to community visions and motivators (or the lack thereof) to participate in joint research (Pinto, 2009). Such information enhances the current state of knowledge for researchers and practitioners, provides opportunities for these outsiders to repair traditionally mistrustful relationships, and strengthens motivators that facilitate collaboration.

A primary goal of the current study is to better inform researchers and service providers regarding ways that IDUs define their community and how outsiders should effectively and responsibly enter and engage the IDU community. The participating members provided voice for this study and helped identify key concepts for their community. These key concepts include: (a) a better understanding of the meaning, experience and importance of “community” in the everyday lives of Denver’s IDU population; (b) an understanding of how IDUs perceive “community participation,” and in what circumstances they are willing to take an active role in collaborative research; and (c) a foundational analysis that both informs the feasibility of implementing CBPR processes with IDUs while generating ideas for future collaborative projects.



In order to improve the relationship between community members and researchers, researchers need to create a space for dialogue between themselves and vulnerable populations (Wilson & Neville, 2009), which allows researchers to gain respect and a better understanding of the identity of the community of interest. This dialogue may increase individual and community capacity, which includes an "...increased understanding of how to affect change among individuals and within communities, and the development of community mobilization, problem-solving..." (Rhodes, Malow, & Jolly, 2010, p. 178).

The messages from this study are also relevant to service providers for the IDU community. It can be difficult for agencies working on limited budgets to spend their time and resources developing relationships in communities instead of providing immediate action. Service recipients should have input into the identification of needs, the development of programs, the implementation of services provided, and input as to whether these services are effective at meeting identified needs. If recipients are involved in the development process, program services will have more meaning, and thus be more sustainable.

Many underrepresented communities of interest to researchers and service providers are marginalized in mainstream society and have a history of exploitation and traumatic interactions with outsiders. By providing explanations and strategies for successful engagement, among IDUs and all vulnerable populations, there is greater potential to avoid exploitation and misrepresentation involving these communities. While the voices heard in this study come from self-identified IDUs in the Denver Metro area, the message offered is transferable for other marginalized communities. That message is: "Respect."

Respect encompasses: (a) listening, observing, and taking time to get to know members of the community, and not relying on just reading literature about them; (b) being honest with community members and acknowledging that they should be compensated in some way for the expertise they bring to projects; (c) avoiding assumptions of what they need; few issues are "black and white"; (d) returning to the community to verify the accuracy, completeness, and usefulness of data collected.

### **Lessons Learned**

There are obvious challenges to CBPR-based projects. Relationship and partnership development

and maintenance, establishment of trust, identification of key stakeholders, and understanding the community that researchers and service providers are entering often compound the difficulties associated with limited resources and short deadlines (Rhodes, et al., 2010). While scarce resources can be a deterrent to engaging in community partnerships, another challenge is that this type of work forces those who have traditionally had control to relinquish much of it. Finding the best partners for a project can be difficult, especially when service providers or researchers are outsiders to the community, and the community has had historically exploitive relationships with those outsiders. For these reasons, knowing how the partners define community is essential to engagement. This is not a "quick fix" process. It takes time and continual engagement with partners to learn how to best meet each other's needs. Additionally, through the respect and reciprocity that describes authentic engagement, trust can be established, and more sustainable partnerships created (National Institutes of Health, 2011).

### **Implications**

Results of this project provide clinicians, public health practitioners, service providers, policymakers, health educators, and researchers with information for working with IDUs, as an example of an extremely marginalized community. Understanding the challenges and barriers experienced by these individuals assists with development and implementation of initiatives, policies, and programs that can ultimately influence positive changes in health status. Identifying services that are lacking or inaccessible to the community is an important first step toward building awareness for service providers, policymakers, and researchers. Providing information to outsiders of the IDU, or other marginalized communities, about effective strategies to enter and engage those communities is an essential step for developing partnerships. Finally, listening to the voices of communities typically silenced creates a process that is respectful and reciprocal. This will lead to active community involvement in developing partnerships that identify community needs resulting in the initiation of sustainable public health efforts.

### **Limitations**

Results are not representative of all drug users. Not all drug users are IDUs or homeless, nor do all

IDUs utilize the services of local agencies. Although attendees at our community forums confirmed the information we received from the focus groups, it would still be of benefit to acquire additional community input for successful engagement with this community.

## Summary

Marginalized communities provide important educational opportunities for academics and service providers. Talking directly with members of these communities provides valuable information about how they define and describe themselves, their needs, resources, barriers to accessing those resources, and perceptions about those providing services. This information is crucial for successful and sustainable interactions with marginalized groups to improve their health and wellbeing.

## References

Bell, K., & Salmon, A. (2011). What women who use drugs have to say about ethical research: Findings of an exploratory qualitative study. *Journal of Empirical Research*, 6(4), 84–98.

Chilenski, S.M., Greenberg, M.T., & Feinberg, M.E. (2007). Community readiness as a multidimensional construct. *Journal of Community Psychology*, 35(5), 347–365.

Corbin, J., & Strauss, A. (1990). Grounded theory method: Procedures, canons, and evaluation criteria. *Qualitative Sociology*, 13(1), 3–21.

Creswell, J.W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage.

Flicker, S., Travers, R., Guta, A., McDonald, S., & Meagher, A. (2007). Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *Journal of Urban Health*, 84(4), 478–493.

Harm Reduction Action Center. Our Mission. Retrieved from <http://harmreductionactioncenter.org/>.

Hayashi, K., Fairbairn, N., Suwannawong, P., Kaplan, K., Wood, E., & Kerr, T. (2012). Collective empowerment while creating knowledge: A description of a community-based participatory research project with drug users in Bangkok, Thailand. *Substance Use & Misuse*, 47(5), 502–510.

McMilliam, B. & Chavis, D. (1986). Sense of community: A definition and theory. *Journal of Community Psychology*, 14(1), 6–23.

Murphy-Berman, V., Schnoes, C., & Chambers, J.M. (2000). An early stage evaluation model for assessing the effectiveness of comprehensive community initiatives: Three case

studies in Nebraska. *Evaluation and Program Planning*, 23(2), 157–163.

Mooney-Sommers, J., & Maher, L. (2009). The Indigenous Resiliency Project: A worked example of community-based participatory research. *New South Wales Public Health Bulletin*, 20(7), 112–118.

National Institutes of Health (2011). *Principles of community engagement* (2nd ed.). Bethesda, MD: NIH Publication No. 11-7782.

Paveglio, T.B., Boyd, A.D. & Carrol, M.S. (2016). Reconceptualizing community in risk research. *Journal of Risk Research*, 19(2), 1–21.

Pinto, R. (2009). Community perspectives on factors that influence collaboration in public health research. *Health Education Behavior*, 36(5), 930–947.

Reid, R. (2002). Harm reduction and injection drug use: Pragmatic lessons from the public health model. *Health & Social Work*, 27(3), 223–226.

Rhodes, S.D., Hergenrather, K.C., Wilkin, A.M., & Jolly, C. (2008). Visions and voices: Indigent persons living with HIV in the Southern United States use photovoice to create knowledge, develop partnerships and take action. *Health Promotion Practice*, 9(2), 159–169.

Rhodes, S.D., Malow, R.M., & Jolly, C. (2010). Community-based participatory research (CBPR): A new and not-so-new approach to HIV/AIDS prevention, care, and treatment. *AIDS Education and Prevention*, 22(3), 173–183.

Shaw, A., Lazarus, L., Pantalone, T., LeBlanc, S., Lin, D., Stanley, D., Chepesiuk, C., Patel, S., Tyndall, M., & The PROUD Community Advisory Committee (2015). Risk environments facing potential users of a supervised injection site in Ottawa, Canada. *Harm Reduction Journal*, 12(1), 49.

Sullivan, E., Hassal, P., & Rowlands, D. (2008). Breaking the chain: A prison-based participatory action research project. *The British Journal of Forensic Practice*, 10(3), 13–19.

Tonnies, F. (1957). *Community and society*. Mineola, NY: Dover Publications, Inc.

Viswanthan, M., Ammerman, A., Eng, E., Gartlehner, G., Lohr, K.N., Griffith, D., Rhodes, S., Samuel-Hodge, C., Maty, S., Lux, L., Webb, L., Sutton, S.F., Swinson, T., Jackman, A., & Whitener, L. (2004). Community-based participatory research: Assessing the evidence. *Evidence Reports/Technology Assessments*, No. 99, 1–8. Rockville (MD): Agency for Healthcare Research and Quality.

Wilson, D., & Neville, S. (2009). Culturally safe research with vulnerable populations. *Contemporary Nurse*, 33(1), 69–79.

Wolcott, H.F. (1994). *Transforming qualitative data: Description, analysis and interpretation*. Thousand Oaks, CA: Sage.

### **Acknowledgments**

Appreciation is given to members of the Metro Denver injection drug use community who gave voice to the needs and engagement strategies for this community. We appreciate the staff member involvement and support of the Harm Reduction Action Center. We are grateful to Dayna DeHerrera, a graduate assistant in community health education at the Colorado School of Public Health at the University of Northern Colorado for her efforts in support of this manuscript. Finally, we thank Dr. Jill Bezyak, associate professor of rehabilitation counseling and sciences at the University of Northern Colorado for thoughtful review of this paper. The Colorado Department of Public Health and Environment's Colorado HIV/AIDS Prevention Grant Program provided funding for this project.

### **Human Participant Protection**

This protocol was approved by the University of Northern Colorado Institutional Review Board and the administration of the Harm Reduction Action Center.

### **About the Authors**

Elizabeth D. Gilbert is an associate professor in the Colorado School of Public Health at the University of Northern Colorado. Devin Laedtke is health access coordinator at the University of Colorado, Denver. Teresa A. Sharp is an associate professor in the Colorado School of Public Health at the University of Northern Colorado. Stephanie Wood is a program analyst in the Office of Assessment, Planning and Improvement at the Tacoma Pierce County Health Department in Tacoma, Washington. Lisa Raville is executive director of the Harm Reduction Action Center in Denver, Colorado.